Delivery of high quality stroke and vision care: experiences of UK services.

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Abstract

Purpose: We sought to identify exemplars of high quality care provision from established stroke vision services.

Methods: We identified areas of high quality services across the UK, judged as having integrated stroke/vision care provision for stroke survivors. Healthcare professionals were selected to participate in 1:1 interviews or focus groups. A strengths-weaknesses-opportunities-threats (SWOT) framework was used to lead the discussion in a semi-structured format. Thematic analysis was undertaken.

Results: Interviewees (n=24) from 14 NHS Trusts included eye clinic managers, nurses, orthoptists, occupational therapists and physiotherapists. Identified strengths of their services included established communication, training provision for stroke team staff, 'open access' for referrals, use of standardised screening/referral forms, provision of lay summaries and information sheets, patients assessed on the stroke unit with continued follow-up and initial visual assessments made within one week of stroke onset. Weaknesses included lack of funding, insufficient orthoptic cover, and time consuming retraining of stroke staff because of staff rotation and changes. Opportunities included increasing the number (or length) of orthoptic sessions and training of stroke staff. Perceived threats related to funding and increased appointment waiting times.

Conclusions: Practical elements for improved stroke and vision care provision are highlighted which can be implemented with relatively little financial inputs.

Introduction

Visual impairment is a deficit of visual function and includes abnormalities of central and/or peripheral vision, eye movements and a variety of visual perception problems such as inattention and agnosia[1]. Visual impairment has a direct impact on activities of daily living and quality of life for example through issues with navigation due to poor visual function, reading difficulty, fear of falling, fear of busy environments, necessity for increased caution, loss of independence and social isolation. A care issue exists in relation to visual impairment due to stroke. Vision is not routinely assessed in acute stroke settings and therefore a good understanding of the nature and extent of visual impairment is unknown in order to be able to plan care.

In recent years the Vision In Stroke (VIS) study recruited a large cohort of stroke survivors with visual impairment from across the UK using standardised protocols[1]. This work confirmed that although some visual problems are easily identified, most visual problems are not detected by simply observing the individual and thus require questioning and assessment in order to detect their presence and subsequently make an accurate diagnosis[2]. This supports past reports that visual impairment following stroke may be missed or misdiagnosed[3].

Furthermore visual symptoms are often poorly described by people with stroke. Coexistent communication problems and cognitive impairments can add to the difficulty in identifying those people who have visual problems. Because of the known issues with detecting and diagnosing post-stroke visual impairment, it is important to consider the value of integrated stroke and vision services. Having an

integrated vision service within stroke units can improve the detection of visual problems in stroke survivors leading to earlier visual rehabilitation[4,5].

Current guidelines[6-8] recommend vision care for stroke survivors but recent evidence demonstrates that these recommendations are often not met. Survey evidence shows that many stroke services may fail to deliver optimal vision care. In a survey of current practice by occupational therapists working in Scottish stroke in-patient services, 9% reported access to a protocol for post stroke visual impairment[9]. Choice of treatment was similar regardless of the type of visual impairment present. In a second survey[10] of the current assessment and management strategies used by Scottish orthoptists for post stroke visual impairment, 12% reported access to a protocol or management plan specific to stroke patients. Orthoptists identified lack of a management plan and lack of funding as the main barriers to effective eye care.

A further survey of orthoptists across the UK[11] showed that 45% of stroke services provided no formal vision assessment for stroke patients. The survey found that some services asked when the patient last attended their optometrist for an eye check and considered this to be sufficient for a post-stroke vision assessment: inappropriate when so many visual impairments occur subsequent to the stroke. Furthermore basic screening by nursing, doctor or therapy staff were reported to miss more subtle ocular motility and visual field deficits with a recommendation for formal vision screening by orthoptists and eye care teams. In Scotland, the University of Glasgow best practice statement was recently released (Best Practice Statement 2013)[12]. Their recommendations supported vision screening, full assessment and treatment for cases with visual field loss, eye movement disorders and inattention with use of clear care pathways.

The purpose of this study was to explore the key elements of care provision for post-stroke visual impairment by integrated stroke and vision services.

Methods

Identification of services

"High quality" services were defined as those with designated integrated stroke and vision care provision for stroke survivors incorporating vision screening, full visual assessment and management. We aimed to recruit participants from a total of 15 services perceived to provide a high quality service, where this involved provision of integrated stroke and vision care for stroke survivors.

To identify these services we reviewed clinical study/trial recruitment sites and liaised with the Scottish Stroke and Vision Network. We purposively selected sites which, anecdotally, were reported to provide a high quality service or which, based on involvement in recruitment to recent clinical studies and trials relating to vision and stroke (Vision In Stroke study and Visual Impairment in Stroke: Intervention Or Not (VISION)) were perceived to provide a high quality integrated efficient level of care.

The lead health professional from stroke/vision services in 15 UK Trusts was identified and invited via email to participate in this study. One invitee did not respond. The remainder were provided with written study information and, if interested, they confirmed willingness to participate. Subsequently health care professionals involved in these services were invited to participate in 1:1 interviews or a focus group. Choice of interview or focus group was made on practical grounds.

Where only one individual was available to discuss the service at their Trust, we chose a 1:1 interview method to capture information about their service. Where more than one individual was available, we chose a focus group method in which the group was facilitated to ensure all participants were equally included and had the opportunity to make equal contribution to the discussion.

SWOT (Strenghts, Weaknesses, Opportunities, Threats) framework

A 'SWOT' framework was used to lead the discussion in a semi-structured format. The SWOT framework originated in business use and it can be used in bot profit and non-profit organisations. Its rationale is to gather internal (strengths and weaknesses) and external (opportunities and threats) from which sound decisions can be formulated for services and from which recommendations can be created from studies or surveys. Advantages of the SWOT framework are that it can identify areas in which services are effective, areas which either can or cannot be improved or changed, allows services to identify threats, new risks and put in place measures to mitigate them plus external changes can represent opportunities which services can identify and take advantage of. Furthermore it is a very simple and versatile framework to implement. Disadvantages are that it can fail to analyse factors at a detailed level as analysis can be too simplistic, subjective and not actionable, it can be biased and focuses on gathering information only with potential for lack of prioritization of factors.

Alternative methods to SWOT analysis are focus group facilitation, open interviews with biographical narrative methodology and open surveys. We chose SWOT analysis as a framework to follow in both 1:1 interviews and focus groups to allow parity ad consistency. We specifically sought to identify information on why services

were effective, how services could improve or change, perceived threats and risks with mitigation, opportunities and as we intended to gather information only, were not concerned with the subjective nature of information obtained or any lack of prioritization of the information gathered.

The discussion was structured by establishing the Strengths, Weaknesses, Opportunities and Threats of having formal vision assessments on the stroke unit coupled with follow-up in out-patient eye services thus providing overall vision care and treatment as required for stroke survivors with visual problems. The interview/focus groups were facilitated by one author (FR). A social constructionist theoretical approach was used to guide the interview/focus group; participants were encouraged to express their views and consider their own views in the light of other opinions expressed[13]. The main focus of this approach is to uncover the ways in which individuals and groups participate in the construction of their perceived social reality. It is an on-going dynamic process that is produced by people acting on their interpretations and their knowledge of it. This approach facilitates a means for dialogue, discussion and debate and is concerned with how knowledge is constructed and understood.

The interviews and focus groups were recorded and subsequently transcribed verbatim and anonymised by an independent administrative assistant. The transcribed documents were uploaded to the NVivo 10 software. A thematic approach[13] to analysis of the qualitative data was adopted. Analysis was conducted by one assessor who had also facilitated the interviews and focus groups (FR) and followed the SWOT framework. All 14 transcripts were read with phrases and wording extracted into codes under main headings of strengths, weaknesses, opportunities and threats. They were then reread and coded as a double check

aiming for completeness of information capture. Themes were generated from the codes according to key phrases and wording appearing in the transcripts. Thus themes emerging were transcript driven and not researcher driven. Each theme was subsequently refined to generate clear definitions and names of each.

Results

From 15 identified services, twelve 1:1 interviews and two focus groups were conducted with 14 UK NHS Trusts offering an integrated stroke and vision service. Individual interviewees included an eye clinic manager (n=1) and orthoptists (n=11). Focus group interviewees included nurses (n=2), orthoptists (n=2), occupational therapists (n=4) and physiotherapists (n=3). Distribution of these participants is outlined in table 1. Interviews and focus groups took place between 1st September and 30th November 2013. Interviews ranged in duration from 30 to 60 minutes while focus groups ranged from 70 to 90 minutes). Discussions during the interviews centred on perceived strengths, weaknesses, opportunities and threats (SWOT framework) to this specialist service. As the information derived from individual interviews was found to be largely similar to that derived from focus groups, the themes from both interviews and focus groups are presented in combination.

Insert table 1 about here

Strengths

All services considered communication to be key to their success. All provided training for stroke team staff and all provided 'open access' for referrals (i.e. stroke staff could contact the orthoptist at any time to discuss queries and referrals if unsure). All saw patients on the stroke unit with follow-up arranged in the eye clinic and all aimed to undertake initial visual assessments within one week of stroke

onset/admission. All but one service (orthoptist 1:1 interview) used a standardised screening/referral form – either the VIS[1], BIOS[14] or locally designed form. These services had an average of two dedicated sessions (typically 3.75 hours per session) per week for this service ranging from 1-4 sessions per week. Cost analysis for providing these orthoptic sessions is outlined in table 2. These were calculated based on the 2013 agenda for change mid-point salary scales for band 6 and 7 with 20% on-costs.

Insert table 2 about here

The orthoptists in one service (orthoptist 1:1 interview) screened all stroke survivors whereas the remainder had initial vision screening by stroke staff (who had been trained by the orthoptist) followed by secondary screening by the orthoptists. The orthoptist specified the on-going training needs for multidisciplinary members of the stroke team. A second orthoptist (orthoptist 1:1 interview) also emphasised the importance of accurate training. [*Orthoptist in interview: "The stroke staff must retrain annually as a minimum…(it should) not (be) passed on by OT or PT but must be first hand from orthoptics."*]

Half of services provided lay summaries to the stroke teams plus patients and carers in addition to providing vision-specific information leaflet to patients and carers. The lay summaries consisted of information about their visual problem, treatment needed or already provided, follow-up needed or appointment already provided, who the person had been seen by and date of the visual assessment. Individualised patient summaries (often termed 'patient passport') were provided by four services in which patients were provided with details of when they had their vision assessment, the results, any treatment planned and any planned follow-up. One of these orthoptists stated: *"We provide VI information…(these are) our own leaflets plus BIOS leaflets.*

Patients are given a card saying which orthoptist saw them, what their problem is and contact details for the department."] The orthoptist believed this to be highly valuable in their service.

Half of services were able to provide flexible appointments throughout the week and of variable durations. Half of the orthoptists reported being an integral part and a named member of the core stroke team. An orthoptist in a focus group stated: *"There are strong links with stroke team…(we have) first name terms with all and they all know what orthoptists do."*] She felt an integral part of the team and felt valued.

Six orthoptic services maintained a database of all referrals to ensure each patient received assessment and follow-up. [*Orthoptist in interview: "We use a database and diary of all patients referred and seen…we can prioritise the referrals to see most urgent cases first."*] This proved useful where patients were discharged early before vision assessment and ensured patients did not get 'lost' to the service. Four services reported supportive stroke physicians as being vital to their success and four services reported being able to provide a rota of orthoptist staff as essential to ensure coverage of the service despite annual leave or sick leave. In one focus group an occupational therapist stated: *"Doctors are on board which makes a difference. There is a driving force for support (for the vision service)."*] This was endorsed by the rest of the group.

Weaknesses

Lack of funding was raised as a major weakness by twelve services. An eye clinic manager in a 1:1 interview stated: *"We have received no additional funding for our services."*] This meant that the service was dropped once funding stopped leaving the stroke unit and its stroke survivors without support for visual problems. In

addition, lack of orthoptic cover during annual leave was an issue. One orthoptist in a 1:1 interview stated: *"There is a lack of cover…(the service) revolves around one orthoptist. There is no cover when on leave."*] She worried about patients on the stroke unit whilst away on leave as there was no alternative cover for her.

Orthoptists identified that retraining of stroke staff on a regular basis because of staff rotation and changes could be time consuming. During one focus group an orthoptist stated*: "Every change-over of staff requires new training."*] Being solely responsible for the stroke/vision service, this was demanding on her time. Conversely an orthoptist in a 1:1 interview stated that annual training provided by orthoptists was essential and, further, that vision training should not be passed on second-hand by therapists.

Services were regarded as more likely to fail where stroke physicians did not 'buy into' or fully support the service. In one focus group a physiotherapist stated*: "Couple of doctors are good but some are not. There is no buy in by doctors and managers at times but others have been very supportive."*] This aligns with comments in 'Strengths' in which support from physicians was identified as important. Where services could only provide one dedicated session per week, there was a perceived risk of missing patients and not being able to screen all patients as quickly as would be preferred with limited time for assessments. Occasional misinformation from stroke teams about visual problems proved problematic to resolve and added to patient confusion.

Opportunities

Services believed opportunities to be present for increased orthoptic sessions because there were sufficient referrals to justify more sessions. Further training of

stroke staff was also seen as an opportunity. Many orthoptists were invited to speak at stroke meetings which was seen as an opportunity to highlight visual problems, what to look for and who to refer to. Orthoptists had used audits of service to demonstrate the continued increase in referrals and wide benefits to patients and staff. Further opportunities were identified for dual assessments with occupational therapists and physiotherapists plus wider involvement with visual rehabilitation officers from sensory support teams. An orthoptist in a 1:1 interview stated*: "There is an opportunity for joint working as not enough of this currently. We want to be more involved with the stroke team…make use of joint assessments with OT and PT. This isn't feasible at present because of time restrictions."*] Her stroke tea was very supportive but she did not have sufficient time to engage with the stroke unit further after the time spent seeing her patients.

Threats

Funding was identified as a threat to provision of these services. An orthoptist in a 1:1 interview stated*: "We have no funding. We have lobbied for years. We do what they can within the service."*] This reiterated the views of the eye clinic manager in 'weaknesses' for lack of funding. This manager also stated a further perceived threat*: "Patients are breaching waiting times for appointments in the stroke vision service."*] This related to increased waiting times for appointments because of increased numbers of referrals, insufficient dedicated sessions or insufficient orthoptic staff. Without funding this would deteriorate further. Lack of support from stroke physicians and from eye clinic managers and/or ophthalmologists was reported.

Through integration of all responses several key factors could be identified that were considered integral to provision of these high quality specialist services. Table 3 outlines these recommendations.

Insert table 3 about here

Discussion

We aimed to explore the strengths, weaknesses, opportunities and threats of services which were perceived to deliver a high quality level of vision care for stroke survivors. A SWOT analysis was undertaken in 14 service interviews across the UK. The differences and similarities of information gained from both 1:1 interviews and focus groups were very similar. Using the SWOT framework resulted in identification of information relevant to all individual services in a structured manner and ensuring a robust capture of information. Advantages and disadvantages of using a SWOT framework ae outlined in the methods. We acknowledge that there is potential for missed topics but to compensate we allowed an open section at the end of interviews or focus groups to capture any other comments the participants might deem relevant. There is also potential for overlapping themes which did occur during our analysis, for example with funding. However it is important to view how this can be considered both positively and negatively.

Funding was reported as the main concern when discussing weaknesses and threats to services along with a lack of orthoptic cover. This is similar to that reported in previous surveys of orthoptists[10]. Provision of a minimum two orthoptic sessions per week was not found to be a costly service as outlined in table 1. However, even with average costs at less than £10000 per annum, it is acknowledged that, in financially challenged services, it can be difficulty to access such additional funds. Without investment in such services and reprioritisation to include vision assessment

within the ‘core’ stroke service, these issues will remain and unmet visual needs of stroke survivors will continue.

Further concerns included insufficient orthoptic cover and retraining needs. Frequent staff changes resulted in loss of knowledge within the team with a requirement for on-going training of new staff which subsequently required further orthoptic time. It was reported that one orthoptist frequently took the lead for the service but required additional cover when on leave to ensure a seamless service. Ensuring such cover is available also ensures capacity training and succession planning: required for any service. A minimum of two orthoptic sessions was noted to provide service for the level of referrals received. This is also a national orthoptic recommendation[14]. Retraining of stroke team staff required regular sessions with the orthoptist which was reported as both a strength and a weakness. Existing online training resources can be used to supplement such training (for example, Stroke Advancing Modules[15], UK Stroke Forum Education and Training[16]) and ensure a wider access to information and resources. Support for the orthoptic service was also seen as imperative to the successful continuation of the service and was needed particularly from stroke physicians and eye clinic managers. This level of support would likely impact on the ability to attract and maintain funding for the service.

On the basis of strengths and opportunities reported by these services, key elements were identified for how a high quality vision and stroke specialist service can be achieved. These included a minimum of two designated integrated orthoptic sessions to care for stroke survivors with visual problems, with flexibility of appointments, good communication with the stroke team, adequate orthoptic cover during leave and provision of information for clinicians, stroke survivors and carers.

National guidelines recommend that stroke survivors with suspected visual problems should be provided with specialist assessment and management[6-8]. The practical elements extracted from the reported strengths and opportunities of our interviews and focus groups add to the information base of what aspects of service provision are required such that the service aspires to best practice. Fundamental to this is the appropriate funding, staff numbers, flexibility, information provision and communication between clinicians, patients and carers.

A limitation of our study is that we considered high quality services to be those with integrated stroke and vision service and acknowledge this to be a subjective judgement. In addition, purposeful selection applied to the identification of services invited to participate in the study. We acknowledge that other high quality services exist in addition to those selected because of their involvement in stroke specialist interest groups or recent research studies and trials. A potential bias in our study is that most information was gathered in 1:1 interviews with orthoptists whereas we conducted just two focus groups with a wide multidisciplinary stroke team which provided a wider view point. However, all reported very similar issues regardless of profession or interview versus focus group setting. A further limitation is that the same author conducting the interviews and focus groups analysed the transcripts. However this is common practice to ensure familiarity with the transcripts. In addition, transcripts were recoded twice to ensure completeness of information capture. We acknowledge that interviews and focus groups can yield different views but choose both based on practical grounds of how many individuals were available at a given time to contribute to this study. Where only one individual was available, we had no option other than to choose a 1:1 interview. Where a number of

individuals were available, we chose a focus group rather than individual interviews with each participant because of time constraints on the participants during working hours. One-to-one interviews allow an in-depth discussion with the individual over a period of time whereas focus groups are more reliant on group dynamics and interactions. However, to generate more in-depth discussion and to allow each participant equal time for contribution, the duration of focus groups was longer than for 1:1 interviews.

Conclusions

This study has demonstrated that there are clear practical elements which may support the provision high quality integrated stroke and vision services, and which could be implemented with relatively little financial inputs. Increased integration of orthoptists within core stroke teams with orthoptists named within the team and local referral pathways may be beneficial to the delivery of a high quality service. There are a number of challenges to the provision of an integrated vision and stroke service; ensuring sufficient orthoptic cover with appropriate funding to ensure 52 week services would address many of the key challenges.

Declaration of interests

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Table 1 Participant characteristics

Participant	Profession	Gender	Interview or Focus group	Main work setting	Location of NHS Trust
1	Orthoptist	Female	Interview	Eye clinic	East Anglia
2	Orthoptist	Female	Interview	Eye clinic	Midlands/Central England
3	Orthoptist	Female	Interview	Eye clinic	Midlands/Central England
4	Orthoptist	Female	Interview	Eye clinic	North East England
5	Orthoptist	Male	Interview	Eye clinic	North West England
6	Orthoptist	Female	Interview	Eye clinic	North West England
7	Orthoptist	Female	Focus group	Eye clinic	North West England
8	Stroke nurse	Female	Focus group	Stroke unit	North West England
9	Occupational therapist	Female	Focus group	Stroke unit	North West England
10	Occupational therapist	Female	Focus group	Stroke unit	North West England
11	Occupational therapist	Female	Focus group	Stroke unit	North West England
12	Physiotherapist	Male	Focus group	Stroke unit	North West England
13	Physiotherapist	Female	Focus group	Stroke unit	North West England
14	Orthoptist	Female	Focus group	Eye clinic	North West England
15	Stroke nurse	Female	Focus group	Stroke unit	North West England
17	Occupational therapist	Female	Focus group	Stroke unit	North West England
18	Physiotherapist	Female	Focus group	Stroke unit	North West England
19	Orthoptist	Male	Interview	Eye clinic	Northern Ireland
20	Orthoptist	Male	Interview	Eye clinic	Scotland
21	Eye clinic manager	Female	Interview	Eye clinic	Scotland
22	Orthoptist	Female	Interview	Eye clinic	South Coast England
23	Orthoptist	Female	Interview	Eye clinic	South Coast England
24	Orthoptist	Female	Interview	Eye clinic	Wales

Table 2 Orthoptic session cost analysis

Number of sessions per week	Mid band 6 salary (with 20% on costs) Per Annum cost	Mid band 7 salary (with 20% on costs) Per Annum cost
1	£3591	£4264
2	£7182	£8529
4	£14364	£17057

Based on the 2013 agenda for change mid-point salary scales for band 6 and 7 with 20% on-costs.

Table 3 Key elements for high quality stroke/vision services

2 designated orthoptic sessions per week (minimum)
Flexible appointments
Formal stroke team training
Formal support from stroke physicians
Lay summaries
Open communication
Orthoptic assessment within one week of stroke onset
Orthoptist named on core stroke team
Provision of visual information leaflets
Rota of orthoptic staff
Standardised referral form
Vision care pathway